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Choice and control for older people using home care services: how far have council-managed personal budgets helped?

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Abstract:

Purpose

This paper reports the experiences of older people who use council-managed personal budgets (PBs) to fund home care services and their satisfaction with the level of choice and control they are able to exercise.

Design/methodology/approach

Data were collected from 18 older people from eight home care agencies across three councils in England. All interviews were semi-structured and face-to face.

Findings

Despite some optimism about improvements in choice and flexibility experienced by older people using home care services, the findings from this small study suggest that the gap between the 'ideal' of user choice and the 'reality' of practice continues to be significant. The level of choice and control older people felt able to exercise to tailor home care services to their personal needs and preferences was restricted to low level choices. Other choices were constrained by the low levels of older people's PBs and council restrictions on what PBs can be spent on. Older people's understanding of limitations in public funding/pressures on agencies and their reluctance to play an active consumer role including willingness to 'exit' from unsatisfactory care arrangements appeared to further challenge the potential for achieving greater choice and control through council-managed PBs.

Originality/value

The English government's policy emphasis on personalisation of care and support and new organisational arrangements for managed PBs aim to promote user choice and control. This is the first study to report the experiences of older people using managed PBs under these new arrangements. The paper highlights areas of interests and concerns that social care staff, support planners and commissioners may need to consider.

Keywords: Older people, home care, managed personal budgets, social care, personalisation, choice and control.

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Introduction

Over the past 20 years, the English government's policy focus has been on supporting people to live independently in their own homes. Personalisation of care and support, first announced in the document Putting People First (Department of Health, 2007), has been the cornerstone of transformation in social care policy. The objective of personalisation is to give every person who receives publicly-funded support choice and control over the shape of that support in all care settings, rather than having to fit into 'one size fits all' services. Personal budgets (PBs) are a mechanism for facilitating personalisation of publicly-funded social care services with a take up target of 70 percent set by the Care Services Minister in October 2012 (ADASS, 2012). The key principle underpinning a PB is that people needing social care support should have knowledge of the amount of the budget and be involved in planning how to use it. PBs are expected to optimise outcomes (Poole, 2006) by giving people more choice and control over how their care needs and preferences are met and by whom. PBs can be taken as cash direct payments (DP) or as funds managed by the council or a third party, known as 'managed personal budget', or a mixture of the two (ADASS, 2010). Where a service provider manages the budget, with day to day arrangements agreed directly between the service provider and the service user, this is called an Individual Service Fund (ISF) (Bennett and Miller, 2009).

With the increase in the use of PBs, councils have introduced changes to increase competition between providers and choice of provider for managed PB holders. Historically councils purchased home care services using block or cost and volume contracts from a small number of providers. These arrangements are currently being replaced in many councils with Framework agreements, whereby the council purchases services from providers at agreed price and quality thresholds but with no guarantee of clients. Framework agreements have been complemented by new council brokers whose remit is to identify Framework agencies with capacity to deliver the care needed by each service user. Under the new arrangements, detailed support plans are to be devised between the agency managers/supervisors and service users, offering the potential for more flexibility and responsiveness than previous, tightly specified time- and- task based service commissioning (Baxter *et al.*, 2013).

Evidence suggests that older people are often unwilling to take on responsibility for managing a cash direct payment and employing their own carers (Riddell *et al.*, 2005; Clarke, 2006; Poole, 2006; Davey *et al.*, 2007; Orellana, 2010). Consequently there has been a marked growth in the number of older people using managed PBs (ADASS 2011). Older people, especially those without informal carers (Glendinning *et al.*, 2009), may be the largest group to use managed PBs. A survey of PB holders conducted for the year ending March 2012 confirmed 83 percent of older people receiving social care support had managed personal budgets (Routledge and Carr, 2013). Other research has found that older people were more likely to spend a greater proportion of their PBs on essential personal and domestic care than other users (Glendinning *et al.*, 2008; Moran *et al.*, 2012), which implies that personal and home care services will be the dominant type of support that older people will purchase with their PBs. However, evidence from national surveys of PB holders suggests that older people with managed personal budgets are less likely than those with direct payments to report positive outcomes across a number of domains (Hatton and Waters, 2013; Routledge and Carr, 2013). In the interests of equity, it is important that older people using managed PBs do not experience worse outcomes merely because they do not wish to manage their own budget.

Research shows the restrictions of former care management systems in promoting choice (Hardy *et al.*, 1999). Service users had very limited choices over the person providing their services, the tasks that social care services would undertake or the timing of services (Parry-Jones and Soulsby, 2001). Instead, care managers tended to define their needs in terms of what resources were available (Hardy *et al.*, 1999). Where people participated in the design of their care package, this was often reported as being limited to refusing the services or providers offered (Allen *et al.*, 1992; Baldock and Ungerson, 1994). Moreover, while research shows that flexibility is an important aspect of care valued by older people (Henwood *et al.*, 1998; Patmore, 2001; Raynes *et al.*, 2001; Francis and Netten, 2004), evidence suggests a history of low flexibility in home care services for this group, with some home care services strictly limiting activities to those tasks specified by care managers on older people's care plans (Patmore and McNulty, 2002). Francis and Netten (2004) found that among older people using

home care services, many could not request help with tasks beyond those specified on their care plan because they were not on care workers' 'job sheet'. Their research also showed that while some people had never asked for any changes, for many this was not because they did not feel that they needed additional or more flexible help but because they were worried about putting pressure on care workers who they thought were already pressured by tight timetables, or were concerned about asking for something that was not allowed.

Despite policy focus on promoting user choice and control and operational changes to increase choice of provider for managed PB holders, it is still not clear how far new arrangements have delivered choice and control to older people who use council-managed PBs to fund home care services. Given the prevalence of this method of using PBs among older people eligible for publicly-funded social care support, it is important to fill this evidence gap. It is against this background that our paper explores the opportunities reported by a small sample of older people to tailor home care services to their personal needs and preferences and their satisfaction with the level of choice and control they have been able to exercise. This research is the first evidence of the impact of new arrangements on older people's experiences of managed PBs. The evidence from this small study suggests that despite changes aimed at increasing the flexibility and responsiveness of home care services for managed PB holders, the gap between the 'ideal' of user choice and control and the 'reality' of practices continues to be significant for this group.

Method

This paper reports evidence from a study examining factors affecting the delivery of personalised home care services to older people using managed personal budgets (Rabiee, *et al.*, 2013). The study was conducted in three councils that were known to have changed their commissioning and/or delivery arrangements in order to facilitate choice for people using managed PBs. Two of the councils offered Individual Service Funds (ISFs) or their equivalent. In one council all older people opting for a managed PB were automatically given ISFs; in the second council this was only available through a few home care agencies. However, in both

councils PBs remained as indicative allocations held by the council rather than given to home care agencies to manage.

The study was conducted between January 2011 and December 2012. It comprised four stages. Stage 1 involved interviews with council commissioning managers to explore changes in councils' commissioning and contracting for home care services and wider market development activities. Stage 2 involved focus group discussions with council support planners/care managers to explore their experiences of support planning with older people using managed PBs to purchase home care. Stage 3 involved interviews with home care agency managers about their experiences of new arrangements and of providing services to people using managed PBs. Stage 4 involved interviews with older people using managed PBs about their experiences and satisfaction. This paper reports data from the final stage. Other findings are reported elsewhere (Baxter *et al.*, 2013; Rabiee, et al., submitted).

Data collection for this stage of the study took place between August and October 2012. Older people were identified and recruited through a research contact in each home care agency. Interviewees had to be 65 years and over, use council-managed PBs and be without dementia in order to reduce recall problems and be able to give informed consent. Ten agencies across the three sites were approached; each agency was asked to identify up to five potential interviewees. Eight agencies sent anonymised details of a total of 28 older people; managers of the other two agencies said they were too busy to help with recruitment. Twenty-one older people met the research criteria and were invited to take part in the study. Of these, 18 people from eight home care agencies agreed to participate in the study and were interviewed. Of the other three, two were in hospital and one person declined to take part. The interviewees were male (n=3) and female (n=15), between 65 and 98 years old, and from different ethnic groups. Four interviewees lived with their partners; eight lived alone with some family nearby; and six lived alone with no close family. The length of time they had been receiving home care services ranged from six weeks to five years. The number of calls interviewees received each day ranged from one to four. All interviewees except one received care seven days a week.

All interviews were semi-structured, collecting qualitative data, conducted face to face and digitally recorded and transcribed. Interview data were analysed using the framework approach and by a process of data reduction, data display, conclusion drawing and verifying (Miles & Huberman, 1994). The data were summarised onto a series of charts according to analytical categories (both a priori and emergent themes). Conclusions were verified by checking with transcripts and through discussions within the research team. Ethical approval from the Social Care Research Ethics Committee (SCREC) and research governance approvals from the study councils were obtained.

Findings

We asked older people using home care services what they knew about their PB and their experience of exercising choices in relation to the home care services purchased with their budget. In particular we wanted to find out what choices people felt they had been able to exercise over the agency providing the care, the individual care workers delivering the care, the timing of home care visits, the type and range of tasks they received help with; and how they felt about exercising those choices.

Only two of the 18 interviewees seemed to have any knowledge of the budget allocated to them. Two further interviewees reported that knowing how much money was available to them or how many hours of care they were entitled to would be important, as that would give them more control over the budget:

... at least if they can give me feedback as to – every month, say, ‘... we’re supposed to provide for you is 50 hours....For the month, ... You’ve got ten hours or you’ve got five hours for this month, how do you want to use it,’ you know?

[Council 2]

Another interviewee reported:

... if no one tells you what the budget is or what you can do and what – how, you know what I mean, and if that's in the budget to cover ... no one gives you the information. If you ask for it, they say, 'We don't know'.

[Council 2]

Several interviewees said they did not know who was responsible for holding their budget. One person described how this lack of clarity had caused difficulty in setting up an extra lunch time call that had been suggested by hospital staff when she had recently been discharged from hospital:

... They, Social Services said, 'Well, [agency]'s got the budget and so they must have it in. Just if you 've got the money left you can have it anyway' ... [agency] said they haven't got the budget, but Social Services says they have... So I don't know, like – someone said, 'Well, if you had your own budget, then you can – if you want the extra half hour, the money's there, you can do it and if you want to go out, you can do it.' ... But I don't know what the budget is 'cause no one will tell you.

[Council 2]

The following section outlines particular choices that interviewees talked about and the opportunities they said they had to tailor home care services to their personal needs and preferences.

Choice and flexibility over agency

In line with other evidence (Robertson, 1993; Smith *et al.*, 1995; Rabiee and Glendinning, 2010), being able to choose which agency provided their care was not important to most interviewees across all three councils. The majority of interviewees reported being satisfied with the agency they received support from. Such satisfaction did not mean that they had been able to use an agency of their choice. In fact, almost all service users said that the agency had been allocated to them. Indeed, many felt that had they been offered options, they would not have been able

to make a choice because they had no knowledge of the home care market, or were too ill at the time to make a choice.

Choice and flexibility over care workers

Having choice and control over who provided their care was very important to all interviewees but almost all reported that their care workers had been allocated by the agency without any initial discussion before they started receiving the service. However, this did not appear to be an issue of great importance as the older people reported that they had been assured that they would have the opportunity to change their care worker/s if they were not satisfied with them. A few interviewees, from all three study councils, did actually make such changes after they had started using the agency. Poor quality of service was the most common reason reported by interviewees as to why they had asked to have a different care worker. Examples given included care workers turning up late for 'no good reason'; wasting time by making phone calls during visits; and language barriers. Two interviewees who needed help with personal care had changed their female care worker to a male care worker or vice versa. A number of people from minority ethnic groups reported that their religious and cultural preferences were accommodated by home care workers and that was very important to them.

However, most interviewees who were not satisfied with the care worker appeared to put up with them rather than complain and be active consumers willing to 'exit' from an unsatisfactory service. Various explanations were given for their reluctance to complain. Most commonly they did not want to 'make a fuss':

I don't like [pause] complaining. And I won't complain unless I have to complain...
I'll put up with it. I'm not, you know – I don't want to cause any trouble, like, you know... But it sometimes – it annoys my husband sometimes, but it can't be helped... I just go with the flow. It makes it easier, makes it simpler.
[Council 2]

One person explained that she did not want to make a complaint because she thought home care managers were 'bound to believe the carers' rather than her. Others were unsure about how good the service they were getting was, because they had 'nothing to compare it with':

I didn't know what to expect, to be honest with you, 'cause I've never had care before you see... I've got no idea what they normally do anyway

[Council 1]

Almost all interviewees reported having the same small team of care workers, at least during the week and that mattered a great deal to them. They thought that the continuity of care enabled them to develop long term relationships with care workers and, conversely, also gave the care workers a better chance of understanding their own individual needs and preferences. Older interviewees who had established close relationships with their care workers often reported that those relationships had enhanced their choice and control by allowing them to request (or workers to offer) extra 'off-care plan' tasks on an informal basis (for example, doing a bit of shopping, taking the bin out, cleaning and ironing).

Choice and flexibility over tasks

Across the three study sites, users' choices and service responses appeared to be limited to what was stated in interviewees' support plans. While all interviewees said they had a visit prior to using the agency to discuss the kind of help they needed (though not everybody remembered whether that person was from the council or the agency), most people reported that the visit was more about what help they were going to get rather than discussing what help they wanted:

She [agency coordinator] just went through things with me and said, 'This will happen and that will happen ...'... I didn't understand it all to be honest with you, 'cause I've never had dealings with carers.

[Council 1]

Typically, the tasks included in support plans were related to personal care. They included washing, dressing, meal preparation and prompting medication. In the study councils that offered ISF (or its equivalent), there were reports of low level choices over some tasks specified on the care plan (for example, whether to have a sandwich or a ready meal warmed up in the microwave; or whether to have a wash or a shower). These were discussed with the care worker on a day to day basis. Three interviewees reported they could ask their care worker to do something that was not specified on the care plan (for example, cook them a fresh meal). However, they noted that such opportunities were limited because of the short time available in each visit. One person reported that the only time she could have a proper cooked meal was when she had the same care worker for both afternoon and evening visits.

Most interviewees were reluctant to ask their care workers to do any extra tasks for them over and above those stated on their care plan. This was because they felt the care workers were already under a lot of time pressure. Some interviewees reported that agencies were not happy with care workers carrying out 'extra' tasks, over and above those stated on the care plan. Where interviewees talked about care workers doing 'extra' tasks as a favour, they were anxious that such revelations might get the care worker into trouble. Care workers appeared to share these concerns. One service user reported her care worker telling her that 'they [agency managers] shouldn't know that she is doing these things'. Another service user said she once asked her care worker to give her a second bath in one week (which was not in her care plan) and her care worker's response was that she would be sacked if she did that.

Across all three councils, most service users reported wanting more choice and flexibility over how to use their budget:

... the system is good, but it's a bit restricted... because if they had allow, you know, for me to get my own agency, I would then arrange that, like, my ironing and things to be done... because most times in the afternoon, I do have visitors, people come and visit me. So in the afternoon when [care worker] come, you know, at times, she don't have to do anything because if visitors are here, they are already giving me my

tea...so, if I was the one managing it myself I could just easily tell the agency, 'send this person in' ... and then just say, 'I don't want them on Monday...', and use the 45 minutes for them to do a bit of ironing for me.

[Council 2]

Choice and flexibility over the timing and duration of visits

Most interviewees reported that although they had been consulted about their preferred timing of visits, they often received care at times that were either unreliable or inconvenient. There were some reports of workers visiting 'at any time', sometimes earlier and sometimes up to a couple of hours later than expected. While time-keeping was important to all interviewees, the majority accepted care workers not arriving on time. Several people felt that was unavoidable because sometimes clients may need shorter or longer visits. Others were grateful to get the care in the first place and felt that it would be unrealistic to expect punctuality because of the shortages of resources:

I think they are good enough to come and do what they can manage, then I'd better button up a bit...I don't think I should be [critical] because the job they do is a good job and they do what they can for what time they have.

[Council 1]

One person reported that he did not want to 'make a fuss' because of the fear of losing the service which had enabled him to stay at home:

... if I didn't have the care, you know, I would be in a bloody mess. I, have to have it unfortunately; not that I want it, I'm, I'm told that I've got to have it by the Social

people, cos if I argued they would whip me into a bloody hospital or a home....

[Council 3]

The lack of control over the timing of the calls made it difficult for a number of interviewees to make arrangements with family and friends. A few people said they had tried to change the

timing of visits because it interfered with their social life but they had been unsuccessful. In two cases, people reported not being able to make any plans in the evenings because their bed time call was at 7.00pm. For one person, delays in her morning calls made the morning and lunchtime calls very close to one another. Failing to change the timing of her calls, she decided to stop her lunchtime call altogether even though she knew that she would not be able to use this extra/spare time at any other time.

‘Time banking’ is a system whereby time can be saved from routine visits and accumulated for use later. Most interviewees felt that time banking opportunities would be a good way of giving them more control and flexibility. However among these interviewees, opportunities for time banking were limited in both availability and scope. Only a few home care agencies were reported to offer time banking and only three interviewees recruited from those agencies had experienced it. Most interviewees were either not aware of the option or felt that the short time allocated for visits left little leeway to ‘save’ time for use later. Moreover, interviewees reported that unless time banking had already been arranged between them and the agency, it was common for money ‘saved’ from cancelled or shorter visits to be lost rather than remaining in their personal budget. Where time banking did happen, it either involved curtailing the duration of their daily visits or through cancelled visits due to, for example, hospital admissions and holidays.

The time ‘saved’ was used in a range of different ways and the alternative activities were negotiated through the home care agency. One person had decided to shorten her daily visits in order to have a longer visit from the care worker for a shopping trip, to go out to a café or just for a walk. Another interviewee used banked time to have her care worker accompanying her to hospital appointments. She reported that this escort service was easier to manage where there was continuity of care workers because not all care workers were willing to do this. Another interviewee used banked time to ask her care worker to cook a ‘proper’ fresh meal. While time banking was valued by interviewees using these opportunities, one interviewee felt that shortening her routine calls for the benefit of longer calls at a different time made her

routine calls too rushed. She wondered whether it was worth forgoing a cup of tea and 'a bit of a chat' with her care worker for the sake of one trip out a week.

Reviews and monitoring change

Reviews offer formal opportunities to council support planners and agency staff involved in devising support plans to discuss care arrangements with service users and allow users further opportunities to express choices and make changes to support arrangements. Other studies have suggested that service users need to receive home care for several weeks at least before they know what individual adjustments they most want (Colhoun, 1998; Patmore, 2001). However, in line with other research (Netten, 2004), the older people interviewed in this study did not recall having regular reviews. Half the interviewees reported not having had any contact from the local council to check how they were getting on with the home care they were receiving. Three people said they had a yearly review visit from their council. More commonly reviews were carried out by the agency. These ranged from a telephone call or a visit from the agency 'once in a while', to a visit every six or 12 months. A couple of people said that all they had received from the agency was a feedback form with yes/no answers, which they had been requested to fill in and send back once a year. Others reported that they had been asked to contact the agency as and when they had any problem with their home care service.

Discussion and conclusion

The evidence presented in this paper indicates some cautious optimism about improvements in the choice and flexibility experienced by older people using home care services. However, it is important to be cautious in our interpretation of the findings. Firstly, the small sample involved in this study may not be representative of wider populations of older people using managed personal budgets to fund their home care services. In particular, the sample excluded people with dementia so the findings may not be relevant to this group. Hence those taking part in the study may have been more articulate than usual and therefore more able to secure services to suit them. Secondly, improving the quality of home care services has been the focus of a number of policies in England including, the National Minimum Standards for care home (DH,

2003) and Essential Standards of quality and safety (CQC, 2010). Therefore, it is not entirely clear that the cautious optimism indicated by this paper is necessarily the result of new arrangements for managed PB holders. Furthermore, differences between different groups of respondents, for example those living alone and those living with a partner might also make a difference in terms of exercising choice. However, the small size of the sample did not allow making further differentiation between these groups. Given that this was a small scale study, we also need to be cautious about generalising from the findings. However, this paper highlights some areas of interest and concern that social care staff, support planners and commissioners may need to consider.

In summary, we found that, so far as this small sample of older people was concerned, the gap between the 'ideal' of user choice and control and the 'reality' of practice continues to be significant. The choice of agency appeared not to be very important to older people, although it is fundamental to the effective operation of markets and competition. In contrast, opportunities for choice and control over the type and range of tasks, when to receive them and from whom, were important to most interviewees. However, the level of choice and control older people felt they were able to exercise over such issues through managed personal budgets was restricted. Such choices were severely constrained not only by the low levels of older people's PBs and local authority restrictions on what people could use their budget on but also by their lack of knowledge about the amount of their budget.

The operation of the PBs involves interactions between the staff on the one hand, and older people as care receivers, on the other hand. Whether PBs can operate effectively depends not only on whether resources are sufficient to meet older people's care needs and the structural and institutional constraints councils placed on the PBs but also on how older people respond to the PB system and their enthusiasm to play an active consumer role and desire to be involved in the planning of their care. The small study reported in this paper indicate that the sense of exercising real choices among older people is still affected by people's understanding of constraints in public funding and pressures on agencies. Older people's apparent reluctance

to complain in order not to risk compromising relationships with care workers or losing the service further challenge the potential for achieving greater choice and flexibility through PBs. Data from this small study also suggest that review and monitoring procedures may not be as proactive as they could be. Conducting regular reviews is important in ensuring that services continue to be appropriate to users' needs and are responsive to changes in their lives, for example changes in users' health, family circumstances and social networks. Identifying such changes is particularly important for older people who may be reluctant – or, in the case of people with dementia, unable - to take the initiative in asking for changes or voicing their concerns.

The current constraints facing council budgets undoubtedly mean that not all the shortcomings reported by this small sample of older people with council-managed PBs are likely to be resolved without an increase in the levels of PBs. Nevertheless, some steps could be taken, even within the current financial climate, to maximise the potential of PBs in offering greater opportunities for choice and control to this group of PB users. If older people were fully aware of the size of their PB and the amount remaining in their budget, they may be able to exercise more control over how it is spent. Greater freedom is needed to decide how and when to use the PB. More opportunities for time banking, including saving money from cancelled visits, could make a big difference to older people's lives. Proactive, regular reviews would allow older people opportunities to express dissatisfactions which they are otherwise reluctant to voice. While ISFs did seem to allow older people to use their budgets more flexibly, more attention is needed to raise older people's awareness of the opportunities available to them to alter their support arrangements. Last but not least, greater partnership, rooted in trust and good communication, could help to overcome some of the bureaucratic and resource hurdles that are getting in the way for older people with council-managed PBs.

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